



## **End of Life Care August 2003**

1: Alzheimer Dis Assoc Disord. 2003 Apr-Jun;17 Suppl 1:S12-6.

Surrogate decision-making and related issues.

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This article discusses the role of surrogate decision-makers for persons who are cognitively impaired and cannot give informed consent. Questions raised follow. Is surrogate consent in research analogous to proxy consent in health care? What are some issues in surrogate consent? How does the risk-benefit ratio affect the consent process? What are the investigator's responsibilities regarding surrogate consent? Issues discussed include advance directives, durable power of attorney, legally authorized representatives, substituted judgment, double informed consent, responsibilities of surrogates, and barriers to informed consent. The article ends with recommendations to clarify state and national laws, change research designs, and establish a national mechanism for reviewing promising research that is usually prohibited.

PMID: 12813219 [PubMed - indexed for MEDLINE]

2: Am J Bioeth. 2001 Fall;1(4):W10.

The underachieving advance directive: recommendations for increasing advance directive completion.

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Advance directives have failed to achieve a substantial completion rate nationwide despite prior efforts. We hypothesize that the continued low completion rate itself inhibits their utility and application. In this commentary we recommend linking the completion of advance directives to the time when health insurance is initiated or renewed by amending the Patient Self

Determination Act. This would relocate the time and locus of their completion from the emotional turmoil of hospital admission and acute illness to a more equanimous time when family and others can be consulted and involved. Moreover actuating increased utilization may require non-coercive incentives as well as education. Amending the Patient Self Determination Act to require providing advance directive forms at the initiation of healthcare insurance in conjunction with educational and/or incentives could be more effective than the current arrangements.

PMID: 12861997 [PubMed - indexed for MEDLINE]

3: Am J Crit Care. 2003 May;12(3):239-41.

Do-not-resuscitate and stratification-of-care forms in Rhode Island.

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Congress passed the Patient Self-Determination Act of 1990 to ensure that patients are informed of their rights to express healthcare preferences in advance of loss of capacity. Thus, a patient may elect to forgo cardiopulmonary resuscitation in favor of a treatment approach that favors comfort over survival. Do-not-resuscitate and stratification-of-care forms provide a means for expression of healthcare preferences in hospitals. These forms can often guide the important discussion of healthcare preferences. Unfortunately, no clear standard exists for what should be included in do-not-resuscitate or stratification-of-care forms that institutions seeking to improve in this vital area of practice could use for guidance. Existing forms in use at adult general hospitals throughout Rhode Island were reviewed.

PMID: 12751398 [PubMed - indexed for MEDLINE]

4: Am J Geriatr Cardiol. 2003 May-Jun;12(3):207-8.

Ethical issue: The patient undergoes surgery that she knows will not benefit her, hoping that she will die in the process while under anesthesia.

Basta LL.

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PMID: 12732818 [PubMed - indexed for MEDLINE]

5: Am J Hosp Palliat Care. 2003 May-Jun;20(3):229-30.

Breakthrough strong opioid analgesia prescription in patients using transdermal fentanyl admitted to a hospice.

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Durogesic (fentanyl) patches have revolutionized pain relief, but patients still require breakthrough medication. A retrospective analysis of in-patient admission notes at a 25-bed hospice over a six-month period was carried out. Details of analgesia being used on admission for both background and breakthrough pain were obtained, and the appropriateness of the breakthrough dose for those patients using transdermal fentanyl was determined. During the study period 278 patients were admitted to the hospice and 56 (20 percent) were using transdermal fentanyl. Of these, 35 (62 percent) were prescribed strong opioid analgesia--the dose of breakthrough medication prescribed was appropriate in 11 patients (31 percent). Rescue dosing was less than recommended, in relation to prescribed transdermal fentanyl strength in 21 patients (60 percent) and greater than recommended in one patient (3 percent). In this study, short-acting strong opioid analgesia was not always prescribed for patients using transdermal fentanyl, and when they were prescribed, this was in the appropriate dose range in less than a third of patients.

PMID: 12785045 [PubMed - indexed for MEDLINE]

6: Am J Hosp Palliat Care. 2003 May-Jun;20(3):205-10.

Caregivers' satisfaction with hospice care in the last 24 hours of life.

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The goals of this study were to identify elements of care that contributed to positive and negative perceptions of hospice care in the last 24 hours of life, and to define patient and family characteristics that are associated with satisfaction with care during this difficult period. Surveys were sent to 207 primary caregivers, and 112 surveys were returned. This study reports four findings that elucidate the factors that make family members more or less satisfied with the care that their loved one received during the last day of life, and how satisfaction with this period of care should be measured.

PMID: 12785042 [PubMed - indexed for MEDLINE]

7: Am J Hosp Palliat Care. 2003 May-Jun;20(3):221-8.

Integrating complementary and alternative medicine (CAM) into standard hospice and palliative care.

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In the United States, there are 629 million visits to complementary and alternative medicine (CAM) providers each year. Many adults appear to value both conventional and CAM approaches. Because of this public interest and promising evidence that CAM relieves suffering and improves quality of life, we established a program of CAM, known as Integrative Palliative Care (IPC), in a US hospice. This paper outlines our strategy of collaborative relationships with community schools of traditional Chinese medicine (TCM), massage, and harp therapy. It also describes the use of volunteers and small grants and donations to develop and maintain a program of CAM in the hospice setting. The difficulties of research design, problems with tracking outcomes, and the shortcomings of providing therapies with this model are discussed.

Publication Types:

Review

Review, Tutorial

PMID: 12785044 [PubMed - indexed for MEDLINE]

8: Am J Hosp Palliat Care. 2003 May-Jun;20(3):201-4.

Developing end-of-life interdisciplinary programs in universitywide settings.

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Interdisciplinary programs in end of life are widely discussed as valuable, particularly approaches to end-of-life care. Despite this emphasis, interdisciplinary programs have not been easy to implement. In universities, the implementation of interdisciplinary programs encounters administrative obstacles, including credit for the time spent in these group efforts and "ownership" of interdisciplinary courses (IDCs). This article details the process of development and the activities of an end-of-life interdisciplinary program at one urban university with a major medical center. The issues faced in the first year are examined. These included trust, group identity, and communication. The lessons from the first-year activities are presented and efforts of the second year described.

PMID: 12785041 [PubMed - indexed for MEDLINE]

9: Am J Hosp Palliat Care. 2003 May-Jun;20(3):191-200.

Characteristics of dementia end-of-life care across care settings.

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End-of-life care for persons with dementia in different care settings was retrospectively surveyed. In this sample, care recipients receiving hospice care and pain control stayed at home longer and were more likely to die at home. Psychiatric symptoms increased caregiver burden and were the most common reason for admission to an institution, and psychiatric care was associated with longer stay at home. Presence of advance directives decreased hospital stay and increased the likelihood of dying in a nursing home. Care recipients dying at home had fewer symptoms and less discomfort than care recipients dying in other settings. These results indicate that quality end-of-life care can be provided at home and is facilitated by hospice programs, effective pain control, and psychiatric care.

PMID: 12785040 [PubMed - indexed for MEDLINE]

10: Am J Nurs. 2003 Jul;103(7):42-52; quiz 53.

Care at the time of death.

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PMID: 12865640 [PubMed - indexed for MEDLINE]

11: Ann Univ Mariae Curie Sklodowska [Med]. 2002;57(1):439-43.

Palliative care professional education in the new millennium: global perspectives--universal needs.

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In the 20th century, the palliative care is based mostly upon the Anglo-Saxon and Christian contemporary model of care. Is such a model sufficient and could be transformed to the places outside of Judeo-Christian based, west civilization? Is such a model transcultural and could be used for problems solving for those who are professionally involved in the end-of-life care? The universal needs of the dying human being and the family are seen by the authors in the global perspective, and that perspective is tailored as a base for the transcultural model of the education for the professionals within the palliative care.

PMID: 12898957 [PubMed - in process]

12: Arch Intern Med. 2003 Jul 14;163(13):1537-42.

Characteristics of patients requesting and receiving physician-assisted death.

Meier DE, Emmons CA, Litke A, Wallenstein S, Morrison RS.

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**BACKGROUND:** Surveys have shown that physicians in the United States report both receiving and honoring requests for physician assistance with a hastened death. The characteristics of patients requesting and receiving physician aid in dying are important to the development of public policy. **OBJECTIVE:** To determine patient characteristics associated with acts of physician-assisted suicide. **DESIGN:** Physicians among specialties involved in care of the seriously ill and responding to a national representative prevalence survey on physician-assisted suicide and euthanasia were asked to describe the demographic and illness characteristics of the most recent patient whose request for assisted dying they refused as well as the most recent request honored. **RESULTS:** Of 1902 respondents (63% of those surveyed), 379 described 415 instances of their most recent request refused and 80 instances of the most recent request honored. Patients requesting assistance were seriously ill, near death, and had a significant burden of pain and physical discomfort. Nearly half were described as depressed at the time of the request. The majority made the request themselves, along with family. In multivariate analysis, physicians were more likely to honor requests from patients making a specific request who were in severe pain (odds ratio, 2.4; 95% confidence interval, 1.01-5.7) or discomfort (odds ratio, 6.5; 95% confidence interval, 2.6-16.1), had a life expectancy of less than 1 month (odds ratio, 4.3; 95% confidence interval, 1.7-10.8), and were not believed to be depressed at the time of the request (odds ratio, 0.2; 95% confidence interval, 0.1-0.5). **CONCLUSION:** Persons requesting and receiving assistance in dying are seriously ill with little time to live and a high burden of physical suffering.

PMID: 12860575 [PubMed - indexed for MEDLINE]

13: Camb Q Healthc Ethics. 2003 Summer;12(3):279-84.

End-of-life care in Turkey.

Oguz NY, Miles SH, Buken N, Civaner M.

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PMID: 12889333 [PubMed - in process]

14: Can Oncol Nurs J. 2003 Spring;13(2):131-2.

Determining the process of providing quality end-of-life care to hospitalized adult medical patients: the perspectives of nurses.

Thompson G.

University of Manitoba.

PMID: 12793159 [PubMed - indexed for MEDLINE]

15: Chest. 2003 Aug;124(2):771-2.

Another View of End-of-Life Care.

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PMID: 12907579 [PubMed - in process]

16: Chest. 2003 Jul;124(1):392-7.

Comment in:

Chest. 2003 Jul;124(1):11-2.

Dying in the ICU: perspectives of family members.

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**OBJECTIVE:** To describe the perspectives of family members to the care provided to critically ill patients who died in the ICU. **DESIGN:** Multicenter, prospective, observational study. **SETTING:** Six university-affiliated ICUs across Canada. **METHODS:** Patients who received mechanical ventilation for > 48 h and who died in the ICU were eligible for this study. Three to four weeks after the patient's death, we mailed a validated questionnaire to one selected family member who made at least one visit to the patient in the ICU. We obtained self-rated levels of satisfaction with key aspects of end-of-life care, communication, and decision making, and the overall ICU experience. **Main results:** Questionnaires were mailed to 413 family members; 256 completed surveys were returned (response rate, 62.0%). In the final hours before the death of the patient, family members reported that patients were "totally comfortable" (34.8%), "very comfortable" (23.8%), or "mostly comfortable" (32.0%). Family members felt "very supported" (57.0%) and "supported" (30.7%) by the health-care team. Most (82.0%) believed that the patient's life was neither prolonged nor shortened unnecessarily. Most family members (90.4%) preferred some form of shared decision making. Overall, 52% of families rated their satisfaction with care as "excellent," 31% rated care as "very good," 10% as "good," 4% as "fair," and 2% as "poor." Overall satisfaction with end-of-life care was significantly associated with completeness of information received by the family member, respect and compassion shown to patient and family member, and satisfaction with amount or level of health care received. **CONCLUSIONS:** The majority of families of patients who died in participating ICUs were satisfied with the end-of-life care provided. Adequate communication, good decision making, and respect and compassion shown to both the dying patient and their family are key determinants to family satisfaction.

Publication Types:  
Multicenter Study

PMID: 12853551 [PubMed - indexed for MEDLINE]

17: Cleve Clin J Med. 2003 Jun;70(6):548-52.

Withholding nutrition at the end of life: clinical and ethical issues.

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Tube feeding in terminally ill patients has become routine. Indeed, many physicians question the ethics and legality of withdrawal of nutrition and hydration--even in patients whose prospects of recovery are bleak. To avoid unnecessary pain and suffering, patients, physicians, and family members need to discuss the patient's desires, carefully weigh the benefits and burdens of tube feeding, and examine their own beliefs and biases.

Publication Types:  
Review  
Review, Tutorial

PMID: 12828225 [PubMed - indexed for MEDLINE]

18: Correctcare. 2002 Fall;16(4):18.

Dying well in corrections: why should we care?

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PMID: 12705265 [PubMed - indexed for MEDLINE]

19: Developing World Bioeth. 2001 Nov;1(2):163-74.

The distribution of medical resources, withholding medical treatment, drug trials, advance directives, euthanasia and other ethical issues: the Thandi case (II).

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PMID: 12872765 [PubMed - indexed for MEDLINE]

20: Geriatr Nurs. 2003 May-Jun;24(3):188-9.

Did I help my patient choose death?

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PMID: 12813440 [PubMed - indexed for MEDLINE]

21: Gerontologist. 2003 Jun;43(3):309-17.

Advance care planning in nursing homes: correlates of capacity and possession of advance directives.

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**PURPOSE:** The identification of nursing home residents who can continue to participate in advance care planning about end-of-life care is a critical clinical and bioethical issue. This study uses high quality observational research to identify correlates of advance care planning in nursing homes, including objective measurement of capacity. **DESIGN AND METHODS:** The authors used cross-sectional, cohort study between 1997 and 1999. Seventy-eight residents (M age = 83.97, SD = 8.2) and their proxies (M age = 59.23, SD = 11.77) were included across five nursing homes. The authors obtained data via chart review, proxy interviews, resident assessments, survey completion by certified nursing assistants, and direct observation of residents' daily behaviors. **RESULTS:** Capacity assessments revealed that most residents could state a simple treatment preference (82.4%), but a sizable number did not retain capacity to understand treatment alternatives or appreciate the consequences of their choice. Global cognitive ability (Mini-Mental State Examination score) was related to understanding and appreciation. When the authors removed the effects of global cognitive ability, understanding and appreciation were related to time spent by residents in verbal interaction with others. Residents were more likely to possess advance directives when proxies possessed advance directives, proxies were less religious, and residents were socially engaged. **IMPLICATIONS:** Assessment of proxy beliefs and direct determination of residents' decisional capacity and social engagement may help nursing home staff identify families who may participate in advance planning for end-of-life medical care. Measures of global cognitive ability offer limited information about resident capacity for decision making. Decisional capacity assessments should enhance the verbal ability of individuals with dementia by reducing reliance on memory in the assessment process. Interventions to engage residents and families in structured discussions for end-of-life planning are needed.

PMID: 12810894 [PubMed - indexed for MEDLINE]

22: Gerontologist. 2003 Jun;43(3):302-8.

Differences in presenting advance directives in the chart, in the minimum data set, and through the staff's perceptions.

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**PURPOSE:** Decisions concerning end-of-life care depend on information contained in advance directives that are documented in residents' charts in the nursing home. The availability of that information depends on the quality of the chart and on the location of the information in the chart. No research was found that compared directives by the manner in which they are collected and summarized in the chart. The goal of the proposed study was to clarify how advance directives are summarized in the patient's record and to clarify how physicians perceive the same advance directives and formal orders. **DESIGN AND METHODS:** The study involved 122 elderly persons who reside in one large (587 beds) nursing home. The authors collected data regarding the advance directives from three sources-Minimum Data Set (MDS), the front cover of the resident's chart, and from inside the chart. **RESULTS:** The rates of documented advance directives found in this study are higher than those reported in the literature. Agreement rates between sources varied as a function of which sources were compared, as well as on the basis of which directive was examined. More specifically, the authors found higher rates of agreement between the information inside the chart and on the cover of the chart than between the MDS and the other two sources. **IMPLICATIONS:** The reasons for discrepancies may lie in the different functions and procedures pertaining to these source documents.

PMID: 12810893 [PubMed - indexed for MEDLINE]

23: Hawaii Med J. 2003 Jun;62(6):128-9.

End-of-life care curriculum for internal medicine residents at the John A. Burns School of Medicine, University of Hawaii.

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PMID: 12886728 [PubMed - in process]

24: Hawaii Med J. 2003 May;62(5):100-3.

Perceptions of a required hospice experience: a comparison of first- and fourth-year medical students.

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As more attention is focused on the need to improve end-of-life care, medical schools are expanding curricula in this area. This paper presents information about a 12-week, 60-hour hospice unit required for first-year medical students between 1989 and 2001, along with a comparison of first- and fourth-year students' perceptions of this unit. Surveyed in summer of 2001 were 111 individuals who had completed the unit: 59 students who had completed the hospice unit in the 2000-01 academic year and 52 graduating students who had completed the hospice unit in the 1997-98 academic year. The survey tapped perceptions of usefulness of the unit, comfort with end-of-life-care knowledge and skills, and suggestions for improvement. Ninety percent of graduating students rated the hospice experience as personally valuable and 81% acceeded its important for medical education, compared to 69% and 65% of first-year students, respectively. Almost all felt that the hospice unit was a useful experience for them as future clinicians. However, there were few differences in comfort with end-of-life skills between the two classes, e.g., almost 90% felt comfortable listening to patients; about 50% felt comfortable with their knowledge of grief/bereavement, symptom control, physical needs and psychosocial needs; and only 25% felt comfortable discussing a patient's terminal illness with the patient and family. The majority of students felt the unit should remain a first-year requirement, but wanted more opportunities to attend dying patients, work with physician role models, and reflect on their experience with death and its meaning.

PMID: 12806789 [PubMed - indexed for MEDLINE]

25: Int J Palliat Nurs. 2003 May;9(5):222-3.

Comment on:

Int J Palliat Nurs. 2003 Apr;9(4):142-9.

A commentary on 'Administration of as required subcutaneous medications by lay carers'.

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Publication Types:

Comment

PMID: 12819600 [PubMed - indexed for MEDLINE]

26: Int J Palliat Nurs. 2003 May;9(5):208-15.

The quality of spiritual care--developing a standard.

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Spiritual care is an important aspect of holistic care. However, it is seldom the subject of audit, or included in quality standards. This article reports on the work of the Trent Hospice Audit Group (THAG) into the development of a quality standard for the assessment, delivery and evaluation of spiritual care. The standard was drafted by a multidisciplinary team and circulated among the THAG user group and other interested specialists, and subsequently revised. Three levels of assessment are defined and the different levels of expertise needed for these assessments identified. Education has been highlighted as a key issue in enabling effective use of the standard package. Although acknowledging possible limitations and the importance of professional judgement, the standard should help provide a consistent approach to assessment, care planning and outcome review of spiritual care.

Publication Types:

Review

Review, Tutorial

PMID: 12819598 [PubMed - indexed for MEDLINE]

27: Issue Brief Health Policy Track Serv. 2002 Dec 31;:1-15.

Providers issue brief: end of life issues: year end report-2002.

Tanner R.

Assisted suicide has emerged as one of the most controversial ethical issues in the medical community, and one that is complicated more by technological advances that have allowed people to live longer. But as policymakers debate assisted suicide policy, state lawmakers must also examine ways to improve pain management and end-of-life care for people who suffer from terminal illnesses.

PMID: 12879884 [PubMed - indexed for MEDLINE]

28: J Am Geriatr Soc. 2003 Aug;51(8):1155-8.

Using the Family Covenant in Planning End-of-Life Care: Obligations and Promises of Patients, Families, and Physicians.

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Physicians and families need to interact more meaningfully to clarify the values and preferences at stake in advance care planning. The current use of advance directives fails to respect patient autonomy. This paper proposes using the family covenant as a preventive ethics process designed to improve end-of-life planning by incorporating other family members-as agreed to by the patient and those family members-into the medical care dialogue. The family covenant formulates advance directives in conversation with family members and with the assistance of a physician, thereby making advance directives more acceptable to the family, and more intelligible to other physicians. It adds the moral force of a promise to the obligation of respecting a patient's preferences about end-of-life care. These negotiations between patient, family, and physician, from early planning phases through implementation, should greatly reduce the incidence of family disagreements on what the patient would have wanted. The family covenant ensures advance directive discussions within the family, promotes and respects the autonomy of other family members, and might even spur others in the family to complete advance directives through additional covenants. The family covenant holds the potential to transform moral quagmires into meaningful moral conversation.

PMID: 12890082 [PubMed - in process]

29: J Am Geriatr Soc. 2003 Jun;51(6):798-806.

How does the timing of hospice referral influence hospice care in the last days of life?

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**OBJECTIVES:** To determine factors associated with the type of hospice care received in the last days of life and, in particular, how the timing of referral influences the use of continuous hospice home care and inpatient hospice care. **DESIGN:** Retrospective cohort study. **SETTING:** Twenty-one hospice programs across seven states under the ownership of one hospice parent provider. **PARTICIPANTS:** Hospice patients who were cared for and died between October 1, 1998, and September 30, 1999 (N = 28,747). **MEASUREMENTS:** Patient sociodemographic and clinical data were merged with use data from the provider's centralized information system to examine the factors associated with the differing levels of hospice care in the last week of life. In the last days of life, patients were classified as having received routine hospice home care only, having received continuous hospice home care, or having died in an inpatient hospice bed. **RESULTS:** Twenty-three percent of the patients received continuous hospice home care during the last week of life, and 34% died in an inpatient hospice bed. Patients with hospice stays of less than 7 days had a lower likelihood of receiving continuous hospice home care than those who had stays of more than 30 days (adjusted odds ratio (AOR) = 0.81, 95% confidence interval (CI) = 0.75-0.87). Patients with hospice stays of 14 days or less had a greater likelihood of dying in an inpatient hospice bed. Furthermore, patients with stays of less than 7 days who were referred from hospitals were six times likelier to die in an inpatient hospice bed than those who were referred from

another source (AOR = 6.40, 95% CI = 5.74-7.14). Patients in nursing homes had a 93% lower likelihood of dying in an inpatient hospice bed than patients in the community without a live-in caregiver (AOR = 0.07, 95% CI = 0.03-0.19). Strong independent associations were observed between several other covariates and the study outcomes, particularly the covariates of which state hospice care was provided in and level of pain intensity. CONCLUSION: Findings suggest that continuous hospice home care in the last week of life is less likely to occur when patients have short hospice stays. Also, the probability of dying in an inpatient hospice bed is substantially greater for patients referred from hospitals and referred closer to time of death. Further work to determine the appropriateness of use of the different levels of hospice care is needed.

PMID: 12757566 [PubMed - indexed for MEDLINE]

30: J Am Geriatr Soc. 2003 Jun;51(6):789-97.

Decisions for hospice care in patients with advanced cancer.

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OBJECTIVES: To identify factors that may influence the decision of whether to enter a hospice program or to continue with a traditional hospital approach in patients with advanced cancer and to understand their decision-making process. DESIGN: Cross-sectional structured interview. SETTING: One community-based hospice and three university-based teaching hospitals. PARTICIPANTS: Two hundred thirty-four adult patients diagnosed with advanced lung, breast, prostate, or colon cancer with a life expectancy of less than 1 year: 173 hospice patients and 61 nonhospice patients receiving traditional hospital care. MEASUREMENTS: Hospice and nonhospice patients' demographic, clinical, and other patient-related characteristics were compared. Multivariate analysis was then conducted to identify variables associated with the hospice care decision in a logistic regression model. Information sources regarding hospice care and people involved in the hospice decision were identified. RESULTS: Patients receiving hospice care were significantly older (average age 69 vs 65 years,  $P = .009$ ) and less educated (average 11.9 vs 12.9 years,  $P = .031$ ) and had more people in their households (average 1.66 vs 1.16 persons,  $P = .019$ ). Hospice patients had more comorbid conditions (1.30 vs 0.93,  $P = .035$ ) and worse activities of daily living scores (7.01 vs 6.23,  $P = .030$ ) than nonhospice patients. Hospice patients were more realistic about their disease course than their nonhospice counterparts. Patients' understanding of their prognoses affected their perceptions of the course of their disease. Hospice patients preferred quality of life to length of life. In the multivariate analysis, lower education level and greater number of people in the household were associated with the decision to enter hospice. A healthcare provider first told most of those who entered hospice about hospice. Families largely made the final decision to enter hospice (42%), followed by patients themselves (28%) and physicians (27%). CONCLUSION: The decision to enter hospice is related to demographic, clinical, and other patient-related characteristics. This study suggests that the decision-making process for hospice care in patients with advanced cancer is multidimensional. The healthcare community may better meet the end-of-life care needs of advanced

cancer patients through enhanced communication with patients and families, including providing accurate prognoses and better understanding of patients' preferences and values.

PMID: 12757565 [PubMed - indexed for MEDLINE]

31: J Am Geriatr Soc. 2003 Jun;51(6):835-40.

Family involvement in end-of-life hospital care.

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**OBJECTIVES:** To examine whether the end-of-life treatment provided to hospitalized patients differed for those who had a family member present at death and those who did not. **DESIGN:** A retrospective cohort analysis. **SETTING:** An urban community hospital. **PARTICIPANTS:** All 370 inpatients who died during a 1-year period. **MEASUREMENTS:** Medical records were examined for whether life-support treatments were provided or withdrawn, occurrence and timing of do-not-resuscitate (DNR) orders, and use of comfort measures such as narcotics and sedation. **RESULTS:** DNR orders were written for 85% of patients. For patients who had a DNR order written, the average time from the DNR order to death was 4.8 days. Only 26% of patients had one or more treatments withdrawn. Sixty-seven percent of patients received narcotics before death, and 22% received sedatives. Patients aged 75 and older and African Americans were less likely to have a family member present at death. After adjusting for age and ethnicity, patients who had a family member present at death were more likely to have DNR orders written, to have treatments withdrawn, and to receive narcotics before death. Patients with a family member present at death also had a shorter time to death after DNR orders were written. **CONCLUSION:** The presence of a family member at death appears to be an indirect measure of family involvement during patients' hospitalization. Family involvement before death may reduce the use of technology and increase the use of comfort care as patients die.

PMID: 12757572 [PubMed - indexed for MEDLINE]

32: J Am Med Dir Assoc. 2003 Mar-Apr;4(2):101-8.

Advance care planning in long-term care facilities.

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Residents of long-term care facilities are at risk of serious medical illnesses and being unable to express choices when difficult treatment decisions must be made. Advance care planning (ACP) allows residents to consider, make, and



communicate their preferences for how medical decisions should be made if they are unable to participate in the decision-making process. This article reviews the three steps in ACP: consideration of options and expression of values, communication of decisions, and documentation of the choices. The article defines and describes the particular value of ACP in long-term care facilities, reviews the literature on successful ACP programs in long-term care, and concludes with practical suggestions on how to develop and implement ACP programs.

Publication Types:

Review

Review, Tutorial

PMID: 12807583 [PubMed - indexed for MEDLINE]

33: J Am Med Dir Assoc. 2003 Jan-Feb;4(1):23-6.

Staff perceptions of end-of-life care in long-term care.

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**OBJECTIVE:** Although residential care/assisted living facilities and nursing homes have increasingly become a significant site of death for older Americans, little is known about staff perceptions of end-of-life care, perceived need for improvement in care, and differences by type of setting. **DESIGN, SETTING, AND PARTICIPANTS:** Ninety-nine staff provided their perceptions of end-of-life care for 99 decedents from 74 residential care/assisted living facilities and nursing homes in four states as part of a larger cohort study. Staff were interviewed retrospectively regarding care provided during residents' last month of life. **MEASUREMENTS:** Staff reported on 11 areas of end-of-life care, describing the importance of each area and the level of improvement they felt was indicated. Weighted "need for change" scores were calculated as the product of perceived importance and need for improvement. **RESULTS:** Both residential care/assisted living and nursing home staff reported a need for more staff education and nursing assistant time, as well as more use of volunteers. The two lowest ranked items for both facility types were involvement of hospice and encouragement for staff to attend funeral services. Nursing home staff perceived a greater need for improvement than residential care/assisted living staff in all 11 areas. **CONCLUSION:** Results underscore the staffing demands of end-of-life care across facility types, and staff desires to be able to provide quality care throughout the dying process.

PMID: 12807593 [PubMed - indexed for MEDLINE]

34: J Am Med Dir Assoc. 2003 Jan-Feb;4(1):16-22.

A profile of residents admitted to long-term care facilities for end-of-life care.



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**INTRODUCTION:** Permanent placement in a Long-Term-Care (LTC) facility following hospitalization or when staying at home is no longer a viable option is the reality for a growing number of Americans. When death is imminent, the specialized knowledge and skill of the hospice team is required and accepted as an important component of end-of-life (EOL) care. The provision of appropriate care at the EOL is contingent on accurate identification of those residents who are approaching the final stage of life. This study describes the prevalence, profile, and survivorship of residents admitted to LTC facilities, using the Minimum Data Set (MDS) designation of being at the EOL. **METHODS:** A descriptive, correlational, retrospective cohort design was used to analyze all residents admitted to certified LTC facilities with hospice contracts in Missouri in 1999. Variables for analysis were selected from the MDS items that are clinically relevant for those residents at the EOL, for example, pain, incontinence, skin condition, activities of daily living (ADLs), depression, and weight loss. In addition, items regarding advance directives, use of special treatments, and diagnoses were selected because they are important to the care of residents at the EOL. **RESULTS:** Of 492 eligible facilities, 159 were confirmed as providing hospice care. Of 9615 admissions to these facilities, 432 (4.5%) met the EOL care definition; half of these were receiving specialist hospice care. The EOL residents were distinguishable in terms of symptoms. Median survival time for EOL admissions was 33 days. At 6 months, only 17% of EOL admissions remained in the facility. **CONCLUSIONS:** Residents designated as EOL who are admitted to LTC are a distinct group from other new residents, with identifiable needs requiring specialist attention. Accurate recognition that EOL is imminent is required for the development of appropriate strategies and resources for care.

PMID: 12807592 [PubMed - indexed for MEDLINE]

35: J Cancer Educ. 2002;18(2):68-72.

Residents from Five Training Programs Report Improvements in Knowledge, Attitudes and Skills after a Rotation with a Hospice Program.

Von Gunten CF, Mullan PB, Harrity S, Diamant J, Heffernan E, Ikeda T, Roberts WL.

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**Background.** The faculty of the Center for Palliative Studies teach residents from 5 different primary care residency training programs who rotate at San Diego Hospice: 3 in Internal Medicine, 2 in Family Medicine. Residents participate in the care of patients in the inpatient care setting and make joint home visits with physicians and other team members. A series of 4 lectures on end-of-life care is given on Tuesday mornings: management of pain, other symptoms, interdisciplinary roles of chaplains, social workers, nurses, and

grief/bereavement are discussed. In addition, there is a Tuesday noon conference that follows a journal club format. Because of scheduling, residents from some programs are not able to attend all lectures and conferences. Methods. A 27-item self-assessment evaluation tool was developed for administration to residents before and after their experience. A total of 65 evaluations for residents rotating in academic year 1997-98 and 1998-1999 were collated and analyzed. Results. When evaluated as a whole, residents noted significant improvements in their ability to assess and treat symptoms, to tell patient/family about the dying process and to care for dying patients at home (range in improvement from 26% to 67%,  $p < 0.05$  using paired t-test). About half of the residents perceived that the content was not available elsewhere in their training. Conclusion. We conclude that a single hospice rotation can effectively contribute to resident education in multiple programs. J Cancer Educ. 2003;18:68-72.

PMID: 12888378 [PubMed - as supplied by publisher]

36: J Health Soc Behav. 2003 Jun;44(2):215-32.

A "good death" for whom? Quality of spouse's death and psychological distress among older widowed persons.

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Ethicists, policy makers, and care providers are increasingly concerned with helping the dying elderly to experience a "good death." A "good death" is characterized by physical comfort, social support, acceptance, and appropriate medical care, and it should minimize psychological distress for the dying and their families. I identify the predictors of death quality and evaluate how the quality of an older adult's death affects the surviving spouse's psychological adjustment six months after the loss. Analyses use Changing Lives of Older Couples (CLOC) data, a prospective study of married persons ages 65 and older. Positive spousal relationships during the final days increase survivors' yearning yet reduce their anger. Having a spouse die a painful death is associated with elevated anxiety, yearning, and intrusive thoughts. The perception of physician negligence is associated with elevated anger. These findings suggest that improved end-of-life care and pain management will benefit both the dying and their bereaved spouses.

PMID: 12866391 [PubMed - indexed for MEDLINE]

37: J Law Med Ethics. 2003 Spring;31(1):130-43.

A comparative study of the law of palliative care and end-of-life treatment.

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**Library Program Office**  
**Office of Information**  
Veterans Health Administration

Publication Types:

Legal Cases  
Review  
Review, Tutorial

PMID: 12762106 [PubMed - indexed for MEDLINE]

38: J Palliat Med. 2003 Apr;6(2):257-64.

The invisible dimension: abuse in palliative care families.

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The family as the unit of care underpins the philosophy and practice of palliative care. Through this model of service delivery, palliative care professionals attempt to provide holistic, quality end-of-life care to terminally ill patients and their families. The research on palliative care families to date, however, constructs the family unit as functional, articulate, cohesive and, thus, able to adapt to the impact of a terminal diagnosis, albeit with professional intervention if required. This notion of the family as monolithic and unproblematic masks the existence of family issues that have the potential to impact negatively on the care that patients receive, and thus constrain the palliative health professional in facilitating quality end-of-life care. Through a review of current literature, this paper identifies such an issue--that of abusive family relationships--which has been hitherto neglected in palliative care research. It is suggested that the issue of abusive family relationships needs to be identified and responded to at some level if the goal of providing holistic care and facilitating a "good death" for all terminally ill people receiving palliative care is to be achieved. The continued invisibility of this issue does not resolve the problem of abuse and could result in the implementation or continuation of practices that may in fact be damaging.

Publication Types:

Review  
Review, Tutorial

PMID: 12854943 [PubMed - indexed for MEDLINE]

39: J Palliat Med. 2003 Apr;6(2):321-6.

The Renal Palliative Care Initiative.

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**Library Program Office**  
**Office of Information**  
Veterans Health Administration

Despite ongoing technological advances, patients with end-stage renal disease (ESRD) have a mortality rate of approximately 23% per year, and comorbid cardiovascular, cerebrovascular, and peripheral vascular disorders often make life on dialysis an ordeal. This patient population needs an improved approach to symptom assessment and control, as well as advance care planning and high-quality palliative care. Families need support during the lifetime and after the death of their loved ones. To address these needs, the Renal Palliative Care Initiative (RPCI) was instituted at Baystate Medical Center, a large tertiary care hospital, and at eight dialysis clinics in the Connecticut River Valley. With the cooperation of a large nephrology practice, the Western New England Renal and Transplant Associates, a core group of physicians, nurses, and social workers were trained in palliative medicine, and charged with the goals of developing and implementing innovative interventions. The RPCI's programs include symptom management protocols, advance care planning, and bereavement services for families and staff. The Initiative is increasing completion of formal advance directives by the patient population, while staff and families are particularly pleased with annual renal memorial services. The RPCI experience has much to offer the practice of nephrology, and it is relevant to ongoing efforts to extend palliative medicine beyond the traditional focus on cancer and AIDS.

PMID: 12854953 [PubMed - indexed for MEDLINE]

40: J Palliat Med. 2003 Apr;6(2):315-20.

Palliative Excellence in Alzheimer Care Efforts (PEACE): a program description.

Shega JW, Levin A, Hougham GW, Cox-Hayley D, Luchins D, Hanrahan P, Stocking C, Sachs GA.

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Hospice is the standard method for providing quality end-of-life care in the United States. However, studies reveal that persons with dementia are infrequently referred to hospice, that barriers exist to increasing hospice utilization in this population, and that patients with dementia would benefit from hospice or hospice-like services earlier in the disease course. The Palliative Excellence in Alzheimer Care Efforts (PEACE) program responds to these deficiencies, striving to improve end-of-life care of persons with dementia and to integrate palliative care into the primary care of patients with dementia throughout the course of the illness. The PEACE program is a disease management model for dementia that incorporates advance planning, patient-centered care, family support, and a palliative care focus from the diagnosis of dementia through its terminal stages. PEACE is coordinated through the primary care geriatrics practice of the University of Chicago. Patients and caregivers are interviewed every 6 months for 2 years, and a postdeath interview is conducted with caregivers. These interviews assess care domains important for the optimal care of persons with dementia and their caregivers. A nurse coordinator reviews interviews and provides feedback to physicians, facilitating enhanced individual care and continuous quality improvement for the practice. Initial feedback suggests patients have adequate pain control, satisfaction with

quality of care, appropriate attention to prior stated wishes, and death occurring in the patient's location of choice. Families voiced similar high marks regarding quality of care. This program demonstrates an innovative model of providing quality palliative care for dementia patients and their caregivers.

PMID: 12854952 [PubMed - indexed for MEDLINE]

41: J Palliat Med. 2003 Apr;6(2):311-3.

Expanding the realm of the possible.

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PMID: 12854951 [PubMed - indexed for MEDLINE]

42: J Palliat Med. 2003 Apr;6(2):293-6.

Now is the time to embrace nursing homes as a place of care for dying persons.

Teno JM.

Publication Types:  
Editorial

PMID: 12854949 [PubMed - indexed for MEDLINE]

43: J Palliat Med. 2003 Apr;6(2):277-81.

Two remarkable dyspneic men: when should terminal sedation be administered?

Lanuke K, Fainsinger RL, DeMoissac D, Archibald J.

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PMID: 12854948 [PubMed - indexed for MEDLINE]

44: J Palliat Med. 2003 Apr;6(2):195-204.

Writing therapy for the bereaved: evaluation of an intervention.

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Bereavement is a risk factor for a wide range of well-documented negative outcomes. As such, a range of sensitive and appropriate interventions are needed to support people adjusting to their new roles and change in identity. Writing has proven to be useful for people adjusting to traumatic experiences. Translating experiences into language and constructing a coherent narrative of the event enables thoughts and feelings to be integrated, leading to a sense of resolution and less negative feelings associated with the experience. Using a writing therapy intervention tailored specifically for bereaved individuals in Western Australia, this study asked: "Does a writing therapy intervention reduce grief, lead to greater health and wellbeing and lead to greater self care for bereaved individuals?" The results indicate that for grief and General Health Questionnaire-30 (GHQ-30) scores there was an overall improvement for all participants regardless of whether participants received the intervention or not. The results for the effect of writing therapy on self-care demonstrate that there is a greater increase in self-care for the intervention group than for the control group; however, this trend does not reach statistical significance. Writing therapy offers a useful, cost-effective, and private way of supporting bereaved individuals who may not practice self-care. The main limitation of the current research is the low number of participants, which limits the generalizability of the results. Future research could be directed toward evaluating the intervention for recently bereaved people or those identified by screening as being particularly vulnerable.

Publication Types:

Clinical Trial

Randomized Controlled Trial

PMID: 12854936 [PubMed - indexed for MEDLINE]

45: J Palliat Med. 2003 Apr;6(2):205-13.

Nursing home physician educational intervention improves end-of-life outcomes.

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CONTEXT: Nursing homes are the setting for one of five deaths in the United States. Unfortunately these deaths are often accompanied by pain and symptoms of discomfort. OBJECTIVE: To determine if an educational intervention designed for nursing home physicians improves the quality of dying for nursing home residents. DESIGN: Prospective measurement of changes in end-of-life medical care indicators. INTERVENTION: Half-day adult educational outreach program, including audit and feedback, targeted at opinion leaders, and quality improvement suggestions. SETTING: Five geographically diverse Maryland skilled nursing facilities with a total of 654 beds. PARTICIPANTS: The terminal care delivered by 61 physicians who cared for 203 dying residents in the 5 facilities was reviewed. An intervention was targeted to medical directors and those physicians with the majority of patients. Twelve physicians participated in the educational program. MAIN OUTCOME MEASURES: Chart documentation of recognition

of possible death, presence of advance directives, pain control, analgesics used, dyspnea control, control of uncomfortable symptoms during the dying process, documented hygiene, documented bereavement support, and total patient comfort. RESULTS: The four nursing facilities that completed the intervention all had significant improvements in end-of-life care outcomes ( $p < 0.001$ ,  $\chi^2$ ). No statistically significant changes were found in any measure in the cohort nursing facility that did not complete the intervention. When we compared residents with hospice services to those without, we found significant increases in documentation of better hygiene, bereavement support, and total patient comfort ( $p < 0.001$ ,  $\chi^2$  for each). CONCLUSIONS: Important terminal care outcomes can be significantly improved by targeting key nursing home physicians with an adult educational program that includes audit and feedback, and quality improvement suggestions.

PMID: 12854937 [PubMed - indexed for MEDLINE]

46: J Palliat Med. 2003 Apr;6(2):215-24.

Predictors of depression and life satisfaction among spousal caregivers in hospice: application of a stress process model.

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Using a stress process model, risk factors (caregiving stressors, caregiver health, and negative social interactions) and protective factors (caregiving appraisals and social resources) were examined as predictors of family caregiver well-being (depression and life satisfaction). Eighty spousal caregivers of hospice patients with dementia or lung cancer completed structured interviews and self-report measures assessing components of the stress process model. Results suggest that objective measures of patient impairment or amount of care provided are not strong predictors of caregiver depression or life satisfaction. Female gender, caregiver health problems, and negative social interactions were risk factors for poorer caregiver well-being. Caregivers who subjectively appraised caregiving tasks as less stressful, who found meaning and subjective benefits from caregiving, and with more social resources had lower depression and higher life satisfaction, even after controlling for patient impairment and caregiver appraisal variables. Regression models accounted for 42% of variance in caregiver depression and 52% of variance in caregiver life satisfaction. Counseling for hospice family caregivers could utilize the stress process framework, and pay particular attention to finding meaning or subjective benefits from caregiving, and remaining active in social roles. Further research providing evidence on caregiver risk and protective factors could improve the conceptual and empirical basis for psychosocial interventions for hospice family caregivers.

PMID: 12854938 [PubMed - indexed for MEDLINE]



47: J Pastoral Care Counsel. 2003 Summer;57(2):131-41.

Spiritual distress at life's end: finding meaning in the maelstrom.

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Recent trends in social research indicate a decline in church attendance and a corresponding increased interest in spirituality. With the aging of the population, attention to end of life care, with its corresponding spiritual concerns and distress, has become a prominent issue. Spiritual distress can be difficult to distinguish from psychological and physical distress and indicates the need for differential diagnostic markers to distinguish between genuine spiritual experience and psychosis related to the physical death process. Further, for hospice patients who are in genuine need of amelioration through pharmacologic suppression, the question of when and how to medicate becomes paramount as the distinction between spiritual process and psychosis becomes less evident. This article is an exploratory attempt to encourage dialogue across interdisciplinary lines and foster participation from alternative therapies representing the spiritual context of the patient. Anecdotal data from hospice professionals representing a variety of disciplines are presented to illustrate and emphasize the need for continued dialogue and research in this important area.

PMID: 12875121 [PubMed - in process]

48: J Perianesth Nurs. 2003 Jun;18(3):203-5.

The advanced directive: a fundamental communication.

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PMID: 12808519 [PubMed - indexed for MEDLINE]

49: JONAS Healthc Law Ethics Regul. 2003 Jun;5(2):25-8.

Personalization as it relates to nurse suffering: how managers can recognize the phenomenon and assist suffering nurses.

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PMID: 12789029 [PubMed - indexed for MEDLINE]



50: JONAS Healthc Law Ethics Regul. 2003 Jun;5(2):42-6.

The unilateral DNR order--one hospital's experience.

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Hospital or institutional policies that guide the activity of nurses in the care of their patients may, at times, be controversial. Nursing staffs often act as gatekeepers of patient care activities and the implementers of institutional policy. When nurses raise questions as to the appropriateness of a given policy statement, the institution should take serious notice and, perhaps, even study the policy outcomes that relate to the concerns expressed by the nursing staff. This article introduces a policy that originally prompted serious concerns by the nursing staff at one institution. The nursing staff voiced their concerns regarding a revision in the DNR policy that would allow physicians to write unilateral do-not-resuscitate (DNR) orders. Because of this, a review of this policy took place and the results were used to dispel unfounded concerns and also to improve the use of the policy. This article may help nursing administrators to understand better the importance of policy-related studies and it may also encourage nurses to question policy statements and guidelines that may present some concerns. Enhanced patient care will ultimately result by such teamwork and scholarly activity.

PMID: 12789032 [PubMed - indexed for MEDLINE]

51: JONAS Healthc Law Ethics Regul. 2003 Jun;5(2):34-41.

Promoting a good death for persons with dementia in nursing facilities: family caregivers' perspectives.

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The experience of dying from Alzheimer's disease (AD) in a nursing home setting is a poorly understood phenomenon. Fifty-seven family member caregivers of persons with Alzheimer's disease, who had died as a resident in a national nursing home chain, participated in a structured telephone interview. Despite the belief that their loved one had died with dignity, 16 out of 57 (28%) family member caregivers believed that their loved one had not experienced a good death. This article reviews the definition of a good death and the six themes of a good death found in the literature: pain and symptom management; clear decision making; preparation for death; completion; contributing to others; and affirmation of the whole person. Five standards for evaluating the quality of an anticipated death are discussed in relation to the experiences of the persons with AD. Finally, recommendations for how nurse administrators and other members of the healthcare team can promote a positive death experience for a person with AD are proposed.

PMID: 12789031 [PubMed - indexed for MEDLINE]

52: N Engl J Med. 2003 Jul 24;349(4):359-65.

Comment in:

N Engl J Med. 2003 Jul 24;349(4):325-6.

Nurses' experiences with hospice patients who refuse food and fluids to hasten death.

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**BACKGROUND:** Voluntary refusal of food and fluids has been proposed as an alternative to physician-assisted suicide for terminally ill patients who wish to hasten death. There are few reports of patients who have made this choice. **METHODS:** We mailed a questionnaire to all nurses employed by hospice programs in Oregon and analyzed the results. **RESULTS:** Of 429 eligible nurses, 307 (72 percent) returned the questionnaire, and 102 of the respondents (33 percent) reported that in the previous four years they had cared for a patient who deliberately hastened death by voluntary refusal of food and fluids. Nurses reported that patients chose to stop eating and drinking because they were ready to die, saw continued existence as pointless, and considered their quality of life poor. The survey showed that 85 percent of patients died within 15 days after stopping food and fluids. On a scale from 0 (a very bad death) to 9 (a very good death), the median score for the quality of these deaths, as rated by the nurses, was 8. On the basis of the hospice nurses' reports, the patients who stopped eating and drinking were older than 55 patients who died by physician-assisted suicide (74 vs. 64 years of age,  $P < 0.001$ ), less likely to want to control the circumstances of their death ( $P < 0.001$ ), and less likely to be evaluated by a mental health professional (9 percent vs. 45 percent,  $P < 0.001$ ). **CONCLUSIONS:** On the basis of reports by nurses, patients in hospice care who voluntarily choose to refuse food and fluids are elderly, no longer find meaning in living, and usually die a "good" death within two weeks after stopping food and fluids. Copyright 2003 Massachusetts Medical Society

PMID: 12878744 [PubMed - indexed for MEDLINE]

53: Nephrol News Issues. 2003 Jul;17(8):28-31.

Palliative care in chronic kidney disease: peer mentoring program personalizes advance directives discussions.

Perry E, Swartz J, Kelly G, Brown SL, Swartz RD.

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Medical professionals in nephrology are trained to think about improving quality

and quantity of life with their patients, but only recently are they being urged to consider ways to improve end-of-life care. For many staff, this still feels contradictory. One nephrologist recently told these authors, "I was trained to help people live, not to help them die." The RWJF Promoting Excellence in End-of-Life Care work group has investigated, accumulated, and designed resources to help renal teams improve in this challenging arena. Peer mentoring is one such powerful resource, and, once in operation, is cost free. In conjunction with renal social work and the renal team, peer mentoring is a wonderful program that can decrease anxiety and preserve caring relationships in our burgeoning dialysis communities.

PMID: 12882109 [PubMed - in process]

54: Nurse Pract. 2003 Aug;28(8):7.

Oncologists and End-of-Life Care.

Cochran H.

Publication Types:  
Letter

PMID: 12902935 [PubMed - in process]

55: Patient Educ Couns. 2003 May;50(1):95-8.

Care not cure: dialogues at the transition.

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Physicians and patients find it hard to communicate when treatment fails to cure or control cancer. Communication barriers include fear of "giving up," losing the medical team, and discussing death. The quality of physician-patient communication affects important outcomes including patient distress, coping, and quality of life, and physician burnout. Communication skills that can be taught, learned, and maintained for physicians at all levels of training, and effective educational programs have been described. Research on communication skills training should focus on the best method of delivery, the "dose-response" effect, and how to measure success of training in complex health care environments.

Publication Types:  
Review  
Review, Tutorial

PMID: 12767593 [PubMed - indexed for MEDLINE]

56: Prof Nurse. 2003 Jun;18(10):547.

Treatment decisions at the end of life.

Moran A.

PMID: 12808850 [PubMed - indexed for MEDLINE]

57: RN. 2003 Jun;66(6):10.

Larger morphine doses may benefit some terminal patients.

Schlismann C.

Publication Types:  
Letter

PMID: 12838898 [PubMed - indexed for MEDLINE]

58: S D J Med. 2003 Jun;56(6):229-30.

Reflections: improving care at the end of life.

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PMID: 12827939 [PubMed - indexed for MEDLINE]

59: Soc Sci Med. 2003 Aug;57(3):465-75.

The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses.

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Alternative ways of caring for seriously ill patients might have implications not only for patients' own outcomes, but also, indirectly, for the health outcomes of their family members. Clinical observation suggests that patients who die "good deaths" may impose less stress on their spouses. Consequently, we sought to assess whether hospice use by a decedent is associated with decreased risk of death in surviving, bereaved spouses. We conducted a matched retrospective cohort study involving a population-based sample of 195,553 elderly couples in the USA. A total of 30,838 couples where the decedent used

hospice care were matched using the propensity score method to 30,838 couples where the decedent did not use hospice care. Our principal outcome of interest was the duration of survival of bereaved widow/ers. After adjustment for other measured variables, 5.4% of bereaved wives died by 18 months after the death of their husband when their deceased husband did not use hospice and 4.9% died when their deceased husband did use hospice, yielding an odds ratio (OR) of 0.92 (95% CI: 0.84-0.99) in favor of hospice use. Similarly, whereas 13.7% of bereaved husbands died by 18 months when their deceased wife did not use hospice, 13.2% died when their deceased wife did use hospice, yielding an OR of 0.95 (95% CI: 0.84-1.06) in favor of hospice use. Our findings suggest a possible beneficial impact of hospice--as a particularly supportive type of end-of-life care--on the spouses of patients who succumb to their disease. Hospice care might attenuate the ordinarily increased mortality associated with becoming widowed. This effect is present in both men and women, but it is statistically significant and possibly larger in bereaved wives. The size of this effect is comparable to the reductions in the risk of death seen in a variety of other modifiable risk factors in women. Health care may have positive, group-level health "externalities": it may affect the health not only of patients but also of patients' family members.

Publication Types:  
Evaluation Studies

PMID: 12791489 [PubMed - indexed for MEDLINE]